# THE NATIONAL INSTITUTE OF NURSING RESEARCH (NINR) ROADMAP IMPLEMENTATION MEETING

## **Integration of NINR Areas of Science with the NIH Roadmap**

January 22-23, 2004

# Democracy Marriott, Bethesda, Maryland

#### INTRODUCTION

The NINR Roadmap Implementation Meeting was convened by <u>Dr. Patricia A. Grady</u>, Director. This meeting was the first of its kind at NIH, with interdisciplinary experts from around the nation gathering to strategize about best methods to integrate NINR's research priorities and activities into a new structure – the NIH Roadmap. The participants (see participant list on page 11 of this document) were known for their creative thinking, depth of knowledge of the research process, NIH, and nursing research. Special introductions were made: <u>Dr. Dushanka Kleinman</u>, who recently assumed the newly created NIH position of Director for Roadmap Activities, and <u>Dr. Lauren Aaronson</u>, who will have major NINR responsibility for the NINR Roadmap activities. Dr. Aaronson is on an Interagency Professional Agreement from the University of Kansas, where she is Professor and former Research Dean.

The meeting agenda (agenda on page 10 of this document) addressed questions about which Roadmap intersections are natural fits for NINR science, which may be new areas to exploit that would blend with, and enhance, NIH Roadmap goals, and what strategies would engage the NINR research community in Roadmap activities? Overlaying the discussions were five research themes identified in 2003 by NINR, and groups of experts, as the major NINR program areas for the next five plus years. These themes emphasize interdisciplinary research and incorporate the NIH Roadmap activities. The total research sponsored by the NINR is about 90 percent clinical and 10 percent basic. The themes are: Changing Lifestyle Behaviors for Better Health; Managing the Effects of Chronic Illness to Improve Quality of Life; Identifying Effective Strategies to Reduce Health Disparities; Harnessing Advanced Technologies to Serve Human Needs; and Enhancing the End-of-Life Experience for Patients and Their Families. The report on the NINR Research Themes for the Future can be found on the NINR web site.

#### BACKGROUND OF THE ROADMAP

Last year, about 300 individuals contributed expertise to build the <u>NIH Roadmap</u>. This is a new venture championed by <u>Dr. Elias Zerhouni</u> upon assuming his position as NIH Director. The Roadmap focuses on three major areas – Research Themes of the Future; Reinventing the Clinical Enterprise; and New Pathways to Discovery. Although NINR contributions can enhance all three, the first two are particularly pertinent to nursing science. The Roadmap purpose is to move science forward in a synergistic, different way

than in the past – not business as usual, but business as usual plus. Roadmap scientific research is addressed by the agency as a whole, rather than by a single institute, with NIH acting as a catalyst to transform new knowledge to benefit people's health. This new framework of priorities forms a vision of a more efficient, productive way to do research, while defining the most compelling scientific opportunities for research attention. In sum, the purpose is to accelerate the pace of discoveries in the life sciences – to translate sciences more rapidly from laboratories to patients and.

Currently, the NIH Roadmap is somewhere rapidly moving forward. In FY 2004, \$128.3 million is being dedicated to launch Roadmap activities. While this budget is not large, plans call for its steady growth, projected to be \$2.2 billion by FY 2009. All Institutes and Centers (ICs) are contributing funds to the Roadmap, and these contributions will also grow. A number of Roadmap Requests for Applications were issued on the last day of FY 2003. Many are relevant to nursing research. This is the initial call, with a short timeframe for response, since the RFAs will be funded in FY 2004. While the timeframe may be challenging for many, there will be other opportunities in the near future to respond to reissued or new RFAs.

The NIH Roadmap represents a sea change for the NIH research establishment, and will operate alongside NIH's typical research activities. Thus, there will be Roadmap funded initiatives -- and Roadmap-associated and non-Roadmap research operating in tandem outside the Roadmap budget. Present and future mechanisms must be flexible and adapt to Roadmap needs, while also maintaining current and historically important R01s and other funding instruments. The Roadmap will generate new working relationships and scientific partnerships. To succeed, it will break down old habits, barriers, and structures, and stimulate and increase new collaborative activities. The Roadmap will involve interdisciplinary teams undertaking high-risk research. It will emphasize clinical and translational research, and it will enhance the public trust.

In discussing the Roadmap, the group indicated that:

- The Roadmap is an excellent vehicle for communication with Congress. It also provides a yardstick for the future.
- A focus on how to make structural and other changes is needed and should include altering rewards systems to forge partnerships for change.
- Since the Roadmap is far more proactive (more <u>DARPA</u>-like), it should not, as in the past, wait for the right grants to come along to fund; rather, what's urgently needed for public benefit will be decided in advance, and NIH will go out and make science happen. This may increasingly require that contracts and cooperative agreements be used.
- Advocacy groups and constituents need to understand the Roadmap purposes and achievements so that they can support Roadmap funds rather than working to divert funds to other needs.

#### **MECHANISMS**

NINR needs to prepare and stimulate the nursing community to respond to Roadmap challenges. Nursing science is a young science, and researchers have relatively recently become comfortable with current grant mechanisms. They need to be informed of new Roadmap opportunities and assisted in preparing grant applications that will intersect with Roadmap activities.

- Internal, procedural change should take place at NIH in order to implement the Roadmap. An enormous amount of interaction with the outside world will have to occur, including addressing institutional barriers, such as criteria for promotion and journal mastheads. Mechanisms are needed to deal with other communities that will be on Roadmap implementation teams. This needs to have more thought, or team initiatives may revert back to individual grants.
- Contracts and various interagency agreements may need to be used increasingly rather than <u>R01</u>s, particularly for large, expensive endeavors addressing critical health issues.
- Requirements for using a particular instrument such as a <u>Small Business</u> <u>Innovation Research</u> (SBIR) should make clear that having a commercial partner, for example, is required for funding.

#### INTERDISCIPLINARY TEAMS

A premise of the Roadmap is that the complexity of today's and tomorrow's research problems requires team science that moves beyond single disciplines to combine skills and approaches to produce scientific discoveries. Interdisciplinary research has been a special strength of nursing research since its inception.

- To clarify "interdisciplinary," it was indicated that interdisciplinary is not people of different disciplines working in a parallel way on a problem (in silos), it is being a member of an interdisciplinary team that together addresses a problem.
- An example of successful interdisciplinary science is the AIDS crisis, where many disciplines have come together to address this disease.
- Nurse researchers are ideal to lead interdisciplinary teams because of their clinical background. They are the glue the coordinators of care research. They are often perceived as neutral in terms of seeking power and are talented in putting teams together.
- In stimulating interdisciplinary teams, care must be taken not to make individuals feel threatened that something is being taken away from them. They must be shown that team participation will add something to them.
- If interdisciplinary teams are to survive, institutions must change their criteria for evaluating scholarship. NIH is discussing changing its rule on having one Principal Investigator (PI) per research project in favor of multiple PIs.

- Nursing research should increasingly reach out to community and minority members to bring them to the table to participate in the design of research that impacts on them.
- Multiple disciplines may want to apply for grants as teams. Responding to grant calls from the Robert Wood Johnson Foundation, for example, has helped the University of California, San Francisco, create effective interdisciplinary teams.
- Use of interdisciplinary, comprehensive centers was suggested and the Cancer Comprehensive Centers and <u>Academic Health Centers</u> (AHC) were cited as examples. They can act as transducers in cities, States and regions where they are situated. They already have relationships with the people they serve and can more effectively accomplish research objectives.
- Good examples of effective interdisciplinary teams should be identified and highlighted at research meetings such as the State of the Science, CANS, and regional events.

# **Interdisciplinary Training**

- Interdisciplinary training should be emphasized in a variety of settings.
- Multiple disciplines' curricula need to be revised to include interdisciplinary
  endeavors. There should be training in how to form networks and work together.
  Students of multiple disciplines need to be trained in interdisciplinary research at
  a younger age. Best practices need to be identified, and measurement tools of
  successful translation and outcomes should be developed and tested.
- Training is needed on the economic side of health research, including the commercialization process. This will later help in intersecting with the private sector and in translational research.
- Bring in professionals from all disciplines to learn how to work within the new Roadmap environment. This has been done in the basic sciences, but not in the translational sciences.
- Best practice examples of interdisciplinary teams could provide information on how they function, and how they are supported by their institutions—in other words, how the successful succeed.
- A Summer Institute could be created to address Roadmap issues and interdisciplinary research. Multiple NIH ICs could sponsor it. Attendees could include Associate Deans for Research and Assistant Professors. Participants could bring a "buddy" from the university, such as the Vice Chancellor for Research, or a representative of a component of an AHC. This is politically beneficial. These buddies would then also receive training and should be encouraged to collaborate. Industry representatives should also be included, e.g., representatives from the care system, such as those working in long term care.
- The <u>National Association of Community Health Centers</u> should be invited to talk about developing a training program in interdisciplinary community-based research.

#### **LINKAGES**

Considerable discussion centered on linkages – reaching out beyond NIH to involve international collaborators, networks, partnerships, and representatives at the community level in projects and processes connected with the Roadmap. A suggestion made to NIH was to map potential interactions with all possible players and plot a strategy to activate or increase these interactions. NIH and NINR need to play the role of a convener by facilitating discussions and bringing groups together. This role and expectations for success need better definition. Government and NIH development of research versus that done by the private sector needs to be understood in order to develop useful interactions that involve partnerships, division of labor, and collaborations.

#### **International**

- Concern was expressed that the Roadmap not be for "Americans within America," but also involve bridge building with foreign countries. Research should cross national boundaries.
- Fogarty International Center is encouraging foreign collaboration. About 50 percent of RFAs reach beyond the United States. For a number of diseases and conditions, one must conduct research worldwide. Yet much remains to be done in a formal way to increase international linkages.
- Collaborations would be invaluable, and researchers of other countries should intersect with U.S. research teams. There are other paradigms abroad that should be considered in this country ones that would enrich research and improve healthcare over all.
- NINR could be well positioned to use the R01 mechanism to incorporate international sites as part of research studies.

#### **Research Networks**

- Networks are needed across institutions. ICs should work together with each other, with industry, and with foundations. There should be joint databases to develop data collection tools for healthcare.
- Well-developed physician networks should partner with nursing networks, particularly since nurses are knowledgeable in translation research.
- There are about 20 nurse-based practice networks, some of which are funded by <u>AHRQ</u> or deans of Schools of Nursing. More networks are needed. NINR could issue an RFA calling for the networks to generate more research ideas and look at interdisciplinary training and involvement in the community. A practice-based research network could be created for tertiary-based, interdisciplinary facilities around common areas of interest.
- Existing NINR-supported centers could form the skeleton of a network. Rather than creating a new network, why not build from structures that already exist? For example, AHRQ has mounted a successful initiative with nine centers. The <a href="National Institute on Aging">National Institute on Aging</a>, along with NINR, has mounted the <a href="Resource Centers">Resource Centers</a> on <a href="Minority Aging Research">Minority Aging Research</a>. <a href="NIMH">NIMH</a> has the <a href="Minority Mental Health Research">Minority Mental Health Research</a> <a href="Centers">Centers</a>. These centers form critical masses that focus on particular aspects of research, recruit and retain diverse study participants, and involve the community.

## **Partnerships**

- Public/private partnerships are a key Roadmap component. NIH has discussed a
  central forum to facilitate interaction with the private sector. Currently, the
  private sector interacts with all ICs, although individual ICs differ in how they
  interact with these outside groups. NIH has held meetings within the <u>Public</u>
  <u>Health Service</u>, since policy areas in particular require partnerships across various
  public health agencies.
- NINR should use its bully pulpit to launch a summit of professional groups that cover the gamut to become involved in Roadmap activities.
- Public/private interdisciplinary partnerships could be created by NINR to address
  multi-risk behavioral interventions, an area in need of focused research. Health
  disparities would also benefit from public/private partnerships at the community
  level.
- If industry stakeholders are brought together early, they can have a role in developing research and make valuable contributions. This is an area in need of catalyzing.
- In this fiscal climate of anticipated flat budgets, it is critical to partner with industry and foundations, because their contributions will add to NIH's \$27 billion budget. Growth in funds is not going to come from Congress; it will have to come from other sources. If it doesn't happen, there's a danger of internal strife as ICs compete for scarce funds. This could negatively impact the Roadmap.
- Liaisons between the <u>American Association of Colleges of Nursing</u>, the <u>American Association of Medical Colleges</u>, and the <u>AHCs</u> need to be strengthened. On NINR's staff, Dr. Aaronson will be working on strategies to accomplish this.
- In NINR's interaction with industry, thought should be given to commercialization of intellectual property which products and which settings add to the economy? NINR could attract seed money to launch projects.

#### **Collaborations**

• Collaborations among NIH Institutes have grown in recent years. For example, the representative of Brain Institutes Cluster that includes the National Institute of Mental Health, the National Institute of Drug Abuse, the National Institute of Neurological Disorders and Stroke, and the National Institute on Alcohol Abuse and Alcoholism meet together at least once a week to explore common interests. Cultural shifts need to be made, however, at the program level, where people tend to protect the turf that they've been nurturing for a long time. They hesitate to share or release their investigators. The Roadmap is encouraging change by stimulating collaboration among program staffs to work together for some common cause.

#### RESEARCH TRANSLATION

An important Roadmap imperative is to translate research more rapidly from laboratories to patients and back. NINR is already emphasizing translational research. As this research grows and as the Roadmap adds its stimulative effects, society will increasingly experience the benefits. Translational research is critical to achieving the end goal of productive use of research findings to improve people's health. Taxpayers expect and deserve no less.

- There was the impression that little of NIH research from a variety of disciplines has been translated in a meaningful way. This is particularly true in minority communities.
- Translation can be divided into two blocks. One block is how to get the science into the chain of development that leads to something useful. The other block is particularly pertinent to nursing. There is a backlog of existing knowledge that could be applied effectively now. While new discoveries are not necessary for the second block, what is essential is incorporating effective research results in the healthcare system. NINR should intersect with the Roadmap theme Reengineering the Clinical Research Enterprise. Since nurses are the lead healthcare effectors, NINR and its collaborators could focus on training and strategies that could make a real difference.
- A cornerstone of nursing research is translational research from both a science and clinical perspective. "From Neurons to Neighborhood" is an apt catch phrase. It is the nurse scientists and the clinical and community health nurses who communicate with the public and pragmatically translate interventions into everyday practice -- so nurse scientists are playing a role at the neuron level and at the neighborhood level. They advance the science of "community" as well as the science of "culture."
- Translational research is still an underdeveloped area. Yet, everyone expects to be paid whether it takes place or not. Science needs to drive health practice and what gets reimbursed by third party payers. At some point, States and other entities need to say to those providing care here's what interventions will be reimbursed, and here's what will not.

#### NINR ROADMAP AREAS OF RESEARCH

In intersecting with the Roadmap, participants discussed melding the NINR Themes of the Future with Roadmap implementation areas, as well as proposing other research that could enhance Roadmap themes, goals, and strategies. Areas are highlighted below.

NINR should look for situations or problems that have no name. For example, there is no "name" for research that can address patients who have multiple chronic diseases or risks. Too often, research is focused on a patient's single disease or risk, rather than viewing the patient's total physical, mental, and sociological environment. This area can become a future interdisciplinary

- research team topic involving multiple disciplines, industry, technology and communities in a broad way.
- NINR's end-of-life research theme is the area that most distinguishes and sets apart NINR-supported research from that of the other ICs—an area where NINR can remain the leader and stimulate interdisciplinary research as part of the Roadmap.
- Better measurements are needed for behavioral research, even though
  measurements may not be as straightforward as those associated with biological
  issues, such as measuring blood pressure. One of the RFAs calls for supplements
  for <a href="Methodological Innovations in Behavioral and Social Sciences">Methodological Innovations in Behavioral and Social Sciences</a>. NINR and
  interdisciplinary researchers could address, for example, how to use computers to
  assess adherence. The whole area of adherence could be repackaged and made
  into a Roadmap research area.
- **Prevention linked to genetics** is an exciting new area for interdisciplinary research. Why wait for an expression of disease to give treatment, when research on genetics and environmental factors can point to preventive strategies?
- Health issues related to the **aging of the population** represent a compelling problem for research -- not only in terms of longevity and quality of life, but also in economic terms.
- Chronic diseases, including chronic mental illness, are opportune areas for interdisciplinary research. Self-management is an important component of this research. The elderly should receive special emphasis.

#### DISCOVERY RESEARCH

Although the meeting emphasized the first two of the three Roadmap themes – Research Teams of the Future and Re-engineering the Clinical Research Enterprise, nursing research also has a role in New Pathways to Discovery. Dr. Thomas Insel, Director of NIMH, spoke to the group after dinner and stimulated discussion of this area as it pertains to the NINR. Topics of discussion appear throughout this report.

Clarification was provided in differentiating discovery research from other research. Discovery research is descriptive, whereas other research starts out with a clear hypothesis. For example, NIMH wants to contract with someone to map the genes in the mouse brain to determine where they are and when they are expressed. This is descriptive research. Discovery projects can be both urgent and extensive. In order to have a quicker turnaround, contracts should be the preferred mechanism for funding. From its inception, NINR has funded both descriptive and hypothesis-driven research.

### **COMMUNICATION**

Since the NIH Roadmap is new and involves change, communication with the nursing community and the public becomes a necessity.

• The nursing community needs to be better informed about what nursing research is already doing. Successful research models should be identified,

- particularly pertaining to NINR-funded interdisciplinary and translational research projects and findings.
- The Roadmap RFAs should use lay-accessible language, or <u>Plain Language</u> guidelines. Clinicians could advise NIH and NINR about effective ways information should be packaged. Since communication is also a science, research funds could be channeled to investigate effective Roadmap communication strategies.
- The NINR electronic newsletter and the website need to feature Roadmap information. For example, there could be a Roadmap Corner in both. The Roadmap should be featured in NINR speeches, talks and discussions, including information about opportunities, the emphasis on interdisciplinary research across the board, and ways to stimulate collaborative efforts and reach out to stakeholders.
- Other IC Directors could also contribute to NINR communication products by reporting on ways they can partner with NINR.

#### **BARRIERS**

Throughout the group's discussions, barriers needing to be overcome were addressed.

- There is a need to conceptualize where research gaps are, so that the barriers can be circumvented.
- NIH and NINR need to encourage understanding among reviewers that Roadmap projects are more general, are interdisciplinary, and are directed at clinical problems. Reviewers are researchers themselves, and the hypothesis model is typically emphasized. This framework, however, can overlook creative, exciting, novel research proposals. NIH must ensure that those applying for Roadmap RFAs receive an equitable review. The implementation teams will be addressing this complicated issue. NINR and NIH should encourage people who understand the Roadmap goals and needs to apply to be on review panels.
- Traditions, such as single PIs and the way scientific journal mastheads are constructed, need to be changed. Journals need to acknowledge researchers' roles in the studies, rather than list author names in hierarchical order on mastheads. Then the reader can know what each author contributed.

# NINR ROADMAP IMPLEMENTATION MEETING INTEGRATION OF NINR AREAS OF SCIENCE AND THE NIH ROADMAP

#### January 22-23, 2004

# Democracy Marriott, Bethesda, MD AGENDA

#### Thursday, January 22, 2004

1:00 PM	Welcome and Organization of the Meeting	Dr. Patricia Grady
1:30 PM	Presentation of the NIH Road Map Areas of Emphasis Published and Planned Initiatives Presentation of the NINR Themes	Dr. Patricia Grady
2:00 PM	Discussion of the Interaction and Overlap of These Two Perspectives Discussion Leader: Dr. Claudette Varricchio	

Questions to be Addressed:

- What Specific Areas of the Road Map are Most Relevant to NINR Science?
- What Specific Areas of the NINR Themes Best Reflect the Road Map Activities?
- Where is the Area of Greatest Synergy of the Two Perspectives?
- 3:00 PM Questions to be Addressed:

Discussion Leader: Mr. Daniel O'Neal

- What New Directions Should the NINR be Exploring to Take Advantage of Road Map Activities?
- What Areas Should NINR be Suggesting to the Road Map to Increase Nursing Science's Contribution to Achieving the Objectives of the Road Map?
- Which Areas of the Road Map Should Be Seen As Having the Greatest Potential for Impact by NINR?
- 3:45 PM Review/Synthesis of the Areas of Interaction of Road Map and NINR Science Discussion Leader: Dr. Lauren Aaronson

Recommendations for Specific Actions by NINR to Maximize NINR Participation in NIH Road Map Initiatives and to Assure the Representation of NINR Areas of Science in the Road Map Initiatives

6:00 PM Dinner

From Molecules to Man: New Paths to Discovery

Dr. Thomas Insel, Director, NIMH

#### Friday, January 23, 2004

8:00 AM Questions to be Addressed:

Discussion Leader: Dr. Claudette Varricchio

- What Current and Emerging Road Map Topics Are Likely to be Most Compatible with the Capabilities of NINR's Scientific Community?
- How can NINR's Biobehavioral Science Experience and Efforts in Translational Research Best Serve as the Basis for Increasing NINR's Contributions to Future Road Map Initiatives?

9:00 AM Question to be Addressed:

Discussion Leader: Mr. Daniel O'Neal

- What Strategies Could Be Most Effective in Engaging the Nursing Research Community in Road Map Activities?
- What Strategies Should NINR Explore to Enable the Community to be Most Competitive and Contribute to the implementation of the NIH Road Map?

10:30 AM Synthesis and Recommendation

Discussion Leader: Dr. Patricia Grady

11:30 AM Adjournment

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